

End-of-Life Care and the Chaplain's Role on the Medical Team

Article DOI: <http://dx.doi.org/10.5915/43-3-8392>
Video DOI: <http://dx.doi.org/10.5915/43-3-8392V>

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Abstract:

This article depicts a chaplain's role in various learning and teaching situations, including end-of-life care and cases requiring cultural competency and gender preferences. The cases exemplify and underscore the difference between the role of a chaplain and the imam, as well as the necessity to have imams and both male and female chaplains in the hospital. It also describes the training, education, pastoral formation, pastoral identity, and roots of pastoral care in the Islamic tradition. The article explores the challenges of this new profession and advocates having a Muslim chaplain available in the hospital to serve Muslim patients, families, and the non-Muslim staff.

Key words: Islamic ethics, chaplaincy, pastoral care, imam, cultural competency.

Muslim chaplaincy is a new profession for men and women in the field of religion.

On the authority of Anas bin Malik, the servant of the Messenger of Allah, the Prophet Muhammad ﷺ said:

لا يؤمن أحدكم حتى يحب لأخيه ما يحب لنفسه

None of you [truly] believes until he wishes for his brother what he wishes for himself.¹

This hadith underscores the degree of empathy a Muslim should feel for another human. Whether or

not a Muslim chaplain is in the hospital to help family members make meaning out of tragedy or to celebrate a life, he or she embodies Islam's eternal values of empathy, respect, and love of God's creation, dignity, modesty, compassion, and patience in adversity.

Although I have written a few articles about my experiences, there are no statistics or research as yet about this new profession. For example, I was the first Muslim woman to be accepted into the rigorous nine-month residency program at Brigham and Women's Hospital in Boston, Massachusetts, which gives the maximum number of units in clinical pastoral education (CPE). I did my first CPE unit at Saint Vincent Hospital, a small, Catholic hospital in Worcester, Massachusetts, and three CPE units at Brigham and Women's, a much larger, acute trauma hospital.

I studied to become a chaplain to realize a life-long desire to connect deeply with individuals. I am usually standing before an audience giving a speech, but in doing that I am only talking about Islam. After 25 years, I wanted to practice Islam in my every day work. I felt I needed a softer heart and deeper love of God and His Creation. Encouraged by two imams to pursue chaplaincy training, I soon learned about the deep listening and compassionate response required to visit the sick, comfort families, and be present with those grieving, suffering a loss, or experiencing dying or death.

A chaplain's role varies from reminding someone of his or her soul while the thought of the soul is obscured by physical pain to guiding someone to God within their present circumstances. The spiritual dimension can be applied to every aspect of life. For example, when you choose a spouse, you do not just make a spreadsheet of qualities. When you purchase a house, you do not purchase it based on square footage alone. Instead, you are driven by emotion and say, "Ah, this really feels like home." That is the dimension that chaplains nurture in their work. Here, the Qur'an speaks about remembrance of Allah and the effects that has on the heart. The Qur'an says:

الَّذِينَ آمَنُوا وَتَطْمَئِنُّ قُلُوبُهُمْ بِذِكْرِ اللَّهِ
أَلَا بِذِكْرِ اللَّهِ تَطْمَئِنُّ الْقُلُوبُ

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Those who believe, and those whose hearts find their satisfaction in the remembrance of Allah... for without doubt in the remembrance of Allah do hearts find their rest.²

In my life, I wear many hats. Whether acting as a chaplain, speaker, or teacher, I have always been dedicated to participating, initiating, and advocating interfaith relations and dialogue. One of the things I loved about being a chaplain was being able to work on an equal footing with people of other faiths and professions. The position presents yet another opening for Muslims to increase non-Muslims' understanding.

As a new profession for Muslims, chaplaincy raises some important questions about the foundations for pastoral care in Islam. As a Muslim chaplain, it was difficult to form a pastoral identity with no predecessor, no role model, and no research in the field to inform me. In order to form a pastoral identity, students generally draw from a Christian tradition. Therefore, it was incumbent upon me as a student to discover the roots of pastoral care in my own tradition as well as in my personal life.

My identity was imbued by my Arab-American heritage and its value of hospitality. Finding a new purpose for this quality, I saw my role as someone who would welcome and reassure patients. Through the eyes of a new patient, especially an international one, the hospital was a huge, alien, and impersonal institution. I tried to reassure Muslim patients that their religious life would be accommodated during their stay in the hospital, if they wished. For all patients and staff, I tried to provide pastoral care, rooted in the Islamic tradition, as described by M. Fethullah Gulen, who said: "Loving and respecting humanity merely because they are human ... is an expression of love and respect for the Almighty Creator."³

I also encountered the very basic question of what I should call myself; i.e., a title that would indicate to the Muslims what I did and who I was. I spent a lot of time trying to come up with a leadership title other than "iman" to which Muslims could relate. In the end, my authority as a staff member at the hospital sufficed.

Although there is no word in Arabic for "chaplain," chaplaincy has roots in Islamic teachings. A well-known hadith encourages Muslims to visit the

sick and comfort them:

The Messenger of Allah ﷺ said:

قَالَ رَسُولُ اللَّهِ صَلَّى اللَّهُ عَلَيْهِ وَسَلَّمَ إِنَّ اللَّهَ عَزَّ وَجَلَّ يَقُولُ يَوْمَ الْقِيَامَةِ يَا ابْنَ آدَمَ مَرِضْتُ فَلَمْ تَعُدِّي قَالَ يَا رَبِّ كَيْفَ أَغُودُكَ وَأَنْتَ رَبُّ الْعَالَمِينَ قَالَ أَمَا عَلِمْتَ أَنَّ عَبْدِي فُلَانًا مَرِضَ فَلَمْ تَعُدَّهُ أَمَا عَلِمْتَ أَنَّكَ لَوْ عُدَّتَهُ لَوَجَدْتَنِي عِنْدَهُ

Allah ﷻ will say on the Day of Resurrection: 'Son of Adam, I was sick and you did not visit me. The man exclaimed: Lord, how could I visit You, You are Lord of the worlds! Allah will say: Did not you know that My servant, so and so, was sick and you did not visit him? Did not you realize that if you had visited him, you would have found Me with him?'⁴

I found this hadith to be true. As with any conscious act of charity, the act is accompanied by a sense of the Divine presence. Sometimes, I experienced that while meeting patients who displayed a strong faith. They seemed to glow with acceptance, cheer, submission, and made me realize that my faith was not half as strong. Of course, there were those who were ambivalent about faith and forgetful of God. In this case, my job was to be the light in their day, listen to their concerns, uphold their dignity, encourage patience in adversity, and of course, be hopeful for the best outcome.

It was early on when I learned that part of my pastoral formation would involve being a discerning voice for non-Muslims who were caring for Muslim patients and communicating with their families. Many Muslim patients present with three barriers to communication: language, culture, and religion. I noticed that when health-care providers were faced with even one of these differences, it impacted the care of their patient and pace of their treatment. One of the benefits of having a Muslim chaplain on staff was the satisfaction and convenience of consulting and providing whole patient, culturally competent care. Although there seemed to be a prevailing misperception that all Muslims were the same, regard-

less of differences in practice, culture, education, or language, I was still able to provide some degree of information about a patient's religious, cultural, and historical background that was enlightening and helpful.

For example, I was drawn into a family meeting concerning a 34-year-old, non-English speaking Iraqi patient. In chaplaincy training, the family meeting is a special event where one learns how to assess the dynamics between the family and the medical staff, advocate for the family and the staff to ensure that the communication is going well on both ends, and know when to jump in, or when to back off. This was my second meeting, and I was very skeptical that I could be of any help whatsoever because I had only prayed with the patient a few times a week and never had a conversation with him.

The patient had a bone marrow transplant and was suffering from graft versus host disease. He had been sick for months, and it became apparent that he would not get better. Yet, he was being treated aggressively, as per his family's request. It was the nurses on the floor who contacted the hospital ethics committee and asked for a meeting with the family. They complained that in caring for the patient for more than 100 days, his suffering was "unimaginable" and too great to ignore. They threatened to show the family what the patient was really dealing with underneath the covers.

The meeting involved the ethics committee, five of his doctors, a social worker, case manager, two of his nurses, and me, his "chaplain." They asked me to explain to them what religious and cultural influences they should consider as they informed the family that any further medical treatment would be futile.

The patient's wife was invited to the meeting but made it clear to me that she did not want to be the health proxy. The role was a cultural stretch for her. As a result of my interaction with the patient's wife, the committee was prepared for a distant cousin to speak for the patient at the meeting. In my conversation with the wife, I also learned that they were from southern Iraq, where Shia Muslims were persecuted and killed by Saddam Hussein's regime. I shared this information with the committee in advance. Knowing the background somewhat prepared them for the cousin's argument to keep treating the patient. The family listened to the committee's

report, or "reality check," but then concluded that there was no way they could give up hope on the patient. The cousin begged the doctors to continue to treat him. He claimed it was the "Islamic" way because Muslims value life so deeply. He explained that the patient had survived Saddam Hussein's genocide and deserved our continued hope and efforts.

Countering with my limited knowledge of Islam and newly acquired chaplaincy skills, I tried to change his mind, as did every member of the committee. I did not contradict his statement about "the Islamic way." It was, after all, true that we are taught to value life. I did, however, ask if the family had an imam to speak to about the patient's situation. The cousin said they did have an imam and had already spoken to him several times on this matter. After two hours, the meeting ended with the family remaining steadfast and the doctors agreeing to keep treating the patient. When the family left, one of the doctors likened the notion of "never giving up hope" to that used by the families of holocaust survivors. "They never gave up hope then, why should we give up on them now?" After another month, I went to visit this Iraqi patient, only to learn that he had succumbed while I was on vacation.

Chaplains are asked to make notes of each visit in a patient's chart, describing the visit and indicating for the record that they are following the patient. The family of a dying patient might call for a chaplain. If the chaplain is not on duty and the patient is discharged or dies, the family has to settle for a substitute or on-call chaplain at the bedside.

In general, knowledge of a patient's case outcome remains incomplete, except in rare occasions. The main reason is there are too many patients and too few chaplains on the hospital staff. Consequently, the chaplain has to prioritize daily visits. Visiting new patients is a priority, and second visits are discouraged. If a patient leaves the hospital, chaplains generally do not have time to follow up. If a patient dies in the hospital, the chaplain who was with the patient at the time of death makes a bereavement call to the family a week later. In some cases, when the chaplain has had a long relationship with the patient and the family, he or she might be invited to preside over the patient's funeral.

Another thing I learned in my training was the importance for patients to identify their religion as

soon as they are admitted to the hospital. In addition to dietary and modesty needs, knowledge of a patient's religion can impact treatment. As part of our education, we used to attend the "Schwartz Rounds Program" at Brigham and Women's Hospital. The program was founded by a patient, Kenneth Schwartz, a health-care lawyer at Massachusetts General Hospital in 1995, days before he died of lung cancer.⁵ This program's mission was to advance compassionate health care through strengthening relationships between doctors and patients.⁵

The guest speaker demonstrated how cultural and religious incompetence can directly impact the practice of medicine. We watched a video about an elderly Muslim patient from Bangladesh who had colon cancer. The patient wanted to avoid wearing a colostomy bag and asked his doctors not to take out much of his colon. After much discussion among the doctors and with the patient, they agreed to do what he asked. A month later, his family brought him back with evidence of a recurrence. His adult children blamed the doctors for not taking out "all" the cancer. What the children and the patient's doctor did not know was the patient did not want a colostomy bag because he feared he would not be "clean" and therefore would be unable to pray his five daily prayers. I learned that this example underscored the need for a Muslim chaplain on staff. He or she might have clarified a simple misconception and prevented the situation from becoming life threatening.

This case exemplified a communication breakdown, not only culturally between the doctors and the patient, but also between the adult children and the patriarchal, immigrant patient. It is a good example of why it would have been best to employ an imam. As a man, he might have gained the confidence of the male patient. As an imam, trained in pastoral care and experienced in patient care, he might have elicited the patient's true concerns and addressed them.

Another issue to discuss is the role of the chaplain *viz-a-viz* that of the imam. I was contacted by a social worker at Children's Hospital, where a family had requested an imam be present at an impending family meeting. Because the imam was unavailable that day, the social worker called the Brigham and Women's Hospital to see if the Muslim chaplain could fill in. The purpose of the meeting was for the doctor to inform the family that their baby, whom

they had treated for 80 days, was ready to go home, basically to die, because there was nothing more anyone could do.

Speaking with the social worker, I learned as much about the case as I could: the parents had emigrated from Somalia, requested an imam be present at the meeting, required an interpreter for the deaf (father), and another for language. My first reaction was to say, "I think that since they asked for an imam, you need to have an imam present." Although my statement seemed obvious, the social worker's response surprised me. She said, "But what does an imam do, and what is an imam?" She said, "I think it would help me to know more about this in order to know what I should do now."

I explained that an imam would be best in this situation because he was a traditional authority figure with expert knowledge of the religion and that his legitimacy, education, and status in the community could automatically bring comfort to the family and strengthen their faith. I pointed out that asking for an imam was indicative of a custom that needed to be respected. With me substituting for an imam, it might elicit uncomfortable questions like: "Who are you? What is a chaplain? Can a woman do it?" In some circumstances, but not all, these were the questions I heard from the Muslims.

In the end, having been given this information, the social worker was confident enough to postpone the meeting until the imam was available. I made the referral for the imam, so he could be present at the newly scheduled meeting on the next day. Later the imam told me what happened. He said, "It was lucky I was there because the men didn't understand why the baby was going home. They got angry and blamed the mother for wanting to take the baby home of her own volition. I had to explain to them that it was not the mother's idea to take the baby home." They listened to him, and I was glad that he was there to advocate for the woman.

In another case, a 38-year-old woman, a Moroccan immigrant, who was having her fourth child by cesarean, confided in me that she did not want to have any more children. She asked me to ask the imam if it was acceptable for her to have a tubal ligation at the time of the cesarean. She saw me as an intermediary for the imam. As a traditional woman, she did not want to see the imam. So, I arranged for her doctor (a woman) to meet with the imam, and

they discussed all of the options available, including the tubal ligation. My role there was to facilitate the meeting. When all the information was made available to the woman, she and her husband were better able to decide what they wanted to do.

Because I was asked to speak about the role of the chaplain in the end-of-life care, I will share with you a case about an elderly Muslim woman whom I followed for several months as she struggled with terminal congestive heart failure. As there was no cure for this condition the hospitalist suggested to her daughters that they consider hospice at home. He recommended a local hospice group. The patient tacitly agreed.

I was present when the family consulted with a personal family friend, who was an internist. In essence, she told them not to put their mother into hospice under any circumstances. She said, "Your mother will think you have given up hope." She also said that the hospice people came with a "bag of drugs," and warned that at the first sign of the patient failing, they would slip her the drugs, and that would be the end. The doctor-friend carried a lot of weight in the family because she was loved, and she loved and knew the mother well.

Next, they called on the patient's cardiologist, who had been treating her for 20 years. To paraphrase his remarks: Hospice is a beautiful thing. Your mother deserves to have dignity at the end of her life. All her life, she has been fighting and coming back. But now, because there is nothing more that can be done about the heart condition, it is the end of the battle for her. You should honor her by letting her die with dignity.

I sat with the family as they agonized over their dilemma, deciding between two highly respected friends and professionals, who held opposite opinions about hospice. As the family discussed their options, my role was to be a good listener and to make sure everyone's questions were answered and concerns heard. It helped that the patient was of sound mind and made her wishes clear: She did not want to return to the hospital in this condition again.

The patient went home. The case ended sadly, however. A few days later, she fell and broke her hip. She was brought back to the hospital but could not be operated on and died 20 hours later. I was with the patient and her family as she was dying and whispered "Lā ilāha illā Allah," (there is no god but

God) for her because she could not say it out loud and her family was nonpracticing. I also consoled the family and facilitated the funeral arrangements so the patient could be buried as soon as possible in the Islamic tradition.

As for the future of the profession of Muslim chaplaincy, it is a growing profession at all venues. At this time, interest in the Muslim patient, student, prisoner, and soldier is steadily increasing, as the Muslim population grows, assimilates, and the demographics change. I have received many requests to consult and teach on the topic of cultural competency and the Muslim patient and student.

Being hired by a hospital, however, is still on the horizon for a Muslim chaplain, for two reasons: 1) the population of Muslim patients in any one hospital is still very low. In an informal two-month survey that I conducted in my first few months at the Brigham, there were never more than 15 patients in the hospital at any one time. 2) Because hospital budgets are tight, especially in the Pastoral Care Department, directors are forced to choose between hiring a part-time imam or a part-time Muslim chaplain. Although there is a scarcity of imams and fewer still CPE-trained imams, the conventional wisdom in the department is that the hospital is better off hiring an imam, likening the choice as between a priest and a nun. The imam is more traditional, more authentic, and a man. The irony is that it was the two imams I knew who urged me to enter the profession, insisting to me: "We need a woman in the hospital." Although no one has been able to make a strong enough case at this time, most Muslims would agree that women are also needed in the prison, the military, and on college campuses.

As the respective roles of the chaplain and imam continue to evolve, there will always be a need for both in the hospital setting. The chaplain's role in the hospital lends itself to be more of a discretionary one, guiding medical staff as to when to call in the imam. The chaplain's limited role would be complementary for the overworked imam (in scarce supply), leaving him more time to perform other important functions in the Muslim community.

I also see a role for the Muslim chaplain in the mosque community, where families are beset with a bevy of domestic, social, and psychological problems. The Muslim chaplain could provide counseling and pastoral care for adults and children, maintain-

ing confidentiality and giving space to community members who currently suffer silently and needlessly from shame, stress, grief, or sickness.

I hope that young men and women will choose chaplaincy as a profession because it is a unique way to serve Allah and His creation. I believe it is an avenue especially suited for women to offer counseling.

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